

Mark Your Calendar

Support Meetings

First Saturday of the Month

When:

February 1, 2020
 March 7, 2020
 April 4, 2020

Business Meeting

6 - 7 p.m.

Support Meeting

7 - 9 p.m.

Where:

Beaumont Hospital
 Royal Oak Campus
 Administration Bldg.
 Private Dining Room

Special Events:

February 17, 2020

FXAM Playdate
 See page 5.

February 24-25, 2020

Advocacy Day
 Washington, D.C.
 See page 5.

February 29, 2020

Roaring '20s Gala
 See pages 3 and 4.

July 16-19, 2020

17th International
 Fragile X Conference
 Orlando, Florida
 See page 5.

**Fragile X Association
 of Michigan**

FXAM.org

Contact Information:

313-689-3340

contact@fxam.org

Three Cheers for...

Paul



Photo 1: Paul the survivor. Being completely unprepared, Paul struggled with the initial blood draw for a medical test at Rush University Medical Center, Chicago. By the time we were done, it took forty minutes, five people had to hold him down, and one of the tubes hit the floor. Mom and Paul were sobbing and needed an hour to recover.

Photo 2: Preparing for the second blood draw included watching a video (repeatedly) of a boy with autism successfully having a blood draw. We also used numbing cream on Paul's arm, gave him a Zoloft, put on his favorite shirt, took his weighted blanket and favorite pillow, prayed like crazy, and bribed him with a new Xbox game.

Photo 3: Basking in our success! Paul walked into the room like a pro, sat down in the chair and covered himself with his blanket, rested his arm on the pillow, held Mom's hand, watched with fascination at the blood draw, then gave high fives to everyone in the office. It took eight minutes from start to finish. Then he called Dad to find out the "secret code" to his new Xbox game.



Darienne Majeske - for winning the adult category in the 2019 Rare Artist competition. The competition was open to artists with rare disorders/diseases.

University of Michigan Fragile X Clinic

Happy New Year from the University of Michigan Fragile X Clinic!

If you are interested in signing up for the FXCRC FORWARD Registry and Database, or would like to make an appointment for any other reason, please contact us at **734-764-0579**. More information on the Registry and Database can be found online at forwardfx.org/.

2020 Fragile X Clinic Dates

February 20	April 16	May 7
July 16	August 20	September 17
October 15	November 5	December 10

On the Research Front *by Sally Nantais*

Are you looking to participate in research? The National Fragile X Foundation has a great webpage that at a glance you can access a list of studies and search studies to identify current research opportunities. You can filter the opportunities based on:

<u>Study Type</u>	<u>Condition</u>	<u>Travel Considerations</u>	<u>Other</u>
Trial	Fragile X Syndrome	Home	Age
Study	FXTAS	Research Facility	Sex
Survey	FXPOI	Includes Travel Reimbursement	Location
	Premutation Carrier		
	Non-carrier		

Whether you want to participate in a **trial** like *Clinical Trial CONNECT-FX: ZYN002 Gel*
or

A **study** like *Study with Children with Fragile X Syndrome Losing Baby Teeth*
or

A **survey** like *Describing Anxiety for People with Fragile X Syndrome*

Check out **MyFXResearch Portal** at: fragilex.org/our-research/myfxresearch-portal/

I encourage all to get involved, be a Research Hero. The Nantais family participated in their first research study in 2004. Since then, collectively as a family, we have participated in over 50 research opportunities (probably many more, a lot of simple surveys were never documented). And we've not limited our opportunities to Fragile X, a few in the autism arena, or as a caregiver of an individual with intellectual delay and even one on measuring the average woman's knowledge on breast cancer. Please be a Hero!

"Every moment is a fresh beginning."

~ T.S. Eliot



FXAM Roaring '20s Gala honoring Rare Disease Day
Dinner/Dancing/Silent Auction

to be held on a Rare Day - Saturday, February 29, 2020

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We are seeking Gala Sponsors of all levels - from \$29 to \$290 to \$2900 or any amount in between - to help us support FXAM families in multiple ways, especially with International Fragile X Conference Scholarships. All sponsors will be listed in our event program.

We are seeking Silent Auction/Raffle items of all types - rare items would be extra special. All donors will be listed in our event program.

Gala Sponsor of \$_____ to be listed in program as: _____
Mail form with check made payable to: Fragile X Association of Michigan
c/o Mary Beth Langan
51 Greenbriar
Grosse Pointe Shores, MI 48236

Donation of auction/raffle item: _____
(valued at \$_____) Please list donor in program as: _____
For donation pick up, please contact FXAM member _____

Sponsor/Donor _____
Address/City/ZIP _____
Email and Phone _____

Questions about sponsorships, donations and/or attending the gala?
Please contact Mary Beth Langan at mblangan@hotmail.com or 313-689-3340 for more information.

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Thank you for your tax-deductible support of our cause!
The Fragile X Association of Michigan is a 501(c)(3) (Fed. Tax ID# 56-2450171) charitable organization dedicated to raising awareness, supporting research, and aiding families affected by Fragile X Syndrome and other Fragile X-associated disorders.
FXAM.org

What's going on ...

FXAM School Break Playdate

Monday, February 17, 2020
10:30 a.m.

Andrew & Mary Beth will be hosting a playdate at their home.

Come visit, eat lunch, perhaps play UNO or build a puzzle.
Contact Mary Beth at mblangan@hotmail.com or 313-689-3340.



NATIONAL FRAGILE X *FEBRUARY 24-25, 2020*
ADVOCACY DAY

Learn more and register at:

fragilex.org/get-involved/advocacy/nfx-advocacy-day/

FXAM offers a scholarship to help ease your budget if you'd like to participate in the NFXF Advocacy Day in Washington, D.C. This year, the event is February 24-25.

If you would like to apply for the

scholarship, please contact Heather Van Dam at:

heather@stylrite.com

248-343-2077

by **Saturday, February 1**, stating your intention to apply for the scholarship.

ad·vo·ca·cy

the act or process of supporting a cause or proposal. She was known for her advocacy of the Fragile X agenda.

17th International Fragile X Conference

Save the Date!

July 16-19, 2020

Renaissance Orlando at SeaWorld
6677 Sea Harbor Drive, Orlando, FL, 32821

Look for more details at

fragilex.org/get-involved/international-fragilex-conference/

and in our April FXAM newsletter.

Conference Scholarships will be available to help FXAM families attend this unforgettable experience.

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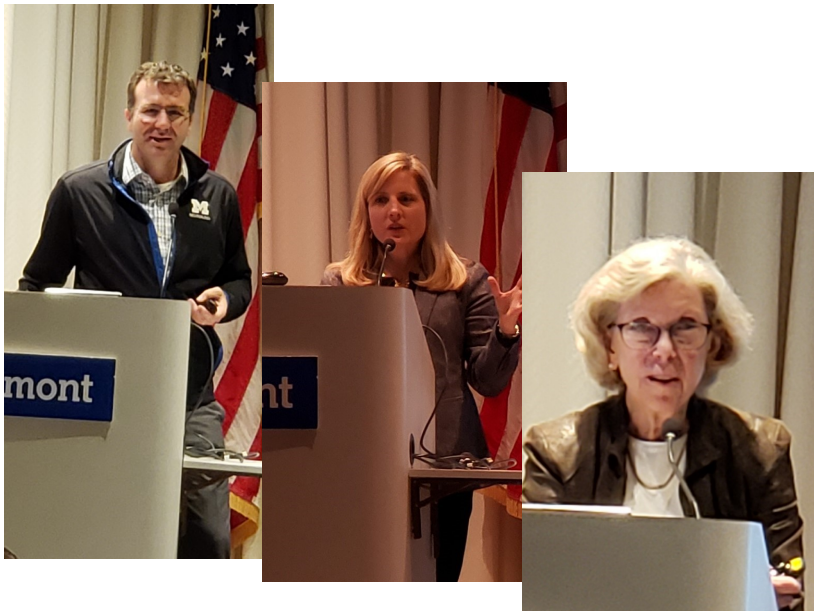
Electronic copies of our newsletter are available on our website.

If you would like to share them with family, friends or professionals, please share our web address with them.

313-689-3340

contact@fxam.org

FXAM.org



Three Cheers for Dr. Todd, Dr. Hall and Dr. Felt for making our FXAM 2019 Mini Conference a success.

 **Fragile X**
Association of Michigan

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